



Site of the new location for Care Project, Antigua.
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Case Study

DISABILITY IN THE CARIBBEAN: SOCIAL INCLUSION CHALLENGES AND THE IMPACT OF SUPPORT PROGRAMS FOR FAMILIES LEARNED FROM ZIKA RESPONSE

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This case study was authored by Morgan Mickle, Kelly Dale, Tisa Barrios Wilson, and Dr. Taroub Harb Faramand of WI-HER, LLC and produced by the USAID Applying Science to Strengthen and Improve Systems (ASSIST) Project, funded by the American people through USAID's Bureau for Global Health, Office of Health Systems. The project is managed by University Research Co., LLC (URC) under the terms of Cooperative Agreement Number AID-OAA-A-12-00101. URC's global partners for ASSIST Zika activities include: American Academy of Pediatricians; FHI 360; Institute for Healthcare Improvement; and WI-HER, LLC. For more information on the work of the USAID ASSIST Project, please visit www.usaidassist.org or write assist-info@urc-chs.com. For more information on gender integration, please write info@wi-her.org.

SUMMARY

Persons with disabilities in the Caribbean have little or no access to health care, rehabilitation, or other specialized support services that children and families affected by Zika need. Since 2018, the USAID Applying Science to Strengthen and Improve Systems (ASSIST) Project has worked to strengthen health systems, specifically newborn, well-baby, and psychosocial support services, in four Eastern and Southern Caribbean countries, as part of USAID's Zika emergency response program in the Caribbean region. WI-HER, LLC, the gender partner for this initiative, has led the gender and social inclusion technical area to integrate inclusive practices into service delivery and throughout the health system. This case study pulls from the global evidence-base to illustrate factors influencing health care access and utilization for persons and families with disabilities, shares findings from two recent gender analysis activities in the Caribbean, and highlights the importance of programs that support families of persons with disabilities in strengthening family health and well-being. Monitoring disability data and the services available at facilities is important in the context of Zika as Zika virus infection during pregnancy can cause severe birth defects, including microcephaly, brain defects, and congenital Zika syndrome. Recent data reveal that children with disabilities make up approximately 1% of the total children's population in Antigua and Barbuda, Dominica, St. Kitts and Nevis, and St. Vincent and the Grenadines, but these numbers could rise as a result of the recent Zika epidemic as affected families are still being identified. Programs targeting families impacted by disabilities can provide many benefits including care assistance, decreased financial burden, increased psycho-emotional support, improved knowledge related to disability care, opportunities for advocacy, and solidarity. As such, programs like these across the Caribbean can be developed or strengthened, and ultimately work towards improving equitable and inclusive health services and well-being of populations in the region.

INTRODUCTION

Social inclusion of persons with disabilities, including children and families affected by Zika, needs to be addressed. Evidence has shown that including persons with disabilities leads to more prosperous societies, promotes human rights of all, and improves overall health and well-being of populations.¹ Working towards inclusion also supports fundamental commitments under the Sustainable Development Goals to “leave no one behind”.² When persons with disabilities are excluded, for example, it can make them more vulnerable to poorer health. For instance, persons with disabilities may experience barriers in accessing health care service or inadequate quality health care.^{3 4} Persons with disabilities in the Caribbean have little or no access to health care, rehabilitation, or other support services.⁵ These are exactly the services that children and families affected by Zika need. According to the CDC, we are still learning the long-term effects of the Zika virus during pregnancy, but early evidence suggests that babies affected may have lasting special needs. Some of the conditions associated with congenital Zika syndrome – such as delays in neurologic or brain development, hearing loss, seizures, vision problems, and challenges with joint and muscles movements – may lead to problems progressing in speaking, learning, moving, and playing.⁶ These babies may need additional tests, exams, and therapies from various specialists; some of which may be difficult to reach or find. The family may also require the assistance of a social worker, insurance provider, friends, and other family and community members to help with transport, care, and services. What is evident looking at long-term care is that raising a child affected Zika can come at a high financial and social costs. This case study focuses on disability and social inclusion in the Eastern and Southern Caribbean and highlights the challenges faced by families raising

children with disabilities – particularly in Antigua and Dominica – and opportunities for strengthening equitable quality care and health systems.

BACKGROUND

According to the World Health Organization’s 2011 World Disability Report, over a billion people (or 15% of the world’s population) are estimated to be living with a disability.⁷ (According to the report, “disability” is defined as an overarching term for impairments, activity limitations, and participation restrictions associated with the interaction between an individual with a health condition and their environment.) The Economic Commission for Latin American and the Caribbean (ECLAC), which has developed three key reports on disability in the Caribbean in particular, highlights that there are over one million persons already living with some form of disability in the Caribbean (250,000 with a significant disability), however little is written about disability in the Caribbean and statistics on persons living with disabilities are limited.^{8 9} Monitoring disability data and the services available at facilities is important in the context of Zika and subsequent response efforts because it has been recognized that Zika virus infection during pregnancy can cause severe birth defects, including microcephaly, other brain defects, and congenital Zika syndrome.¹⁰ This type of data can be useful for early identification of risk factors associated with developmental delays, as well as supporting timely referrals and care.

Specifically, the risk of congenital neurologic defects related to Zika virus infection has ranged from 6 to 42% in various reports. A recent study on pregnancy outcomes after Zika infection in the French Caribbean (French Guiana, Guadeloupe, and Martinique) was conducted between March and November 2016 that tracked the pregnancies of 546 women with confirmed Zika infection. Researchers found that neurologic and ocular defects possibly associated with Zika infection were seen in 7% of the fetuses and infants (39 total). Furthermore, microcephaly was detected in 5.8% of the fetuses and infants (32 total), of whom 1.6% (9 total) had severe microcephaly. Neurologic and ocular defects were more common when Zika infection occurred during the first trimester than when it occurred during the second or third trimester. The findings concluded that birth defects occurred more frequently in fetuses and infants whose mothers had been infected early in pregnancy.¹⁰

Statistics from a 2013 UNICEF survey on children and disabilities in 12 Caribbean countries had noted that children with disabilities accounted for approximately 1% of the total children’s population in Antigua and Barbuda, Dominica, St. Kitts and Nevis, and St. Vincent and the Grenadines, but these numbers could rise as a result of the recent Zika epidemic as affected families are still being identified (see **Figure 1**).¹¹ As a new disease to the region, information and knowledge to reach providers and families has been slow. As more research is being conducted we are learning that developmental delays may show up some time after a child’s initial infection. These factors allude that there could be a faction of families who may not yet know that their child has been affected by the virus. This is important as the implications of Zika can affect a family for their whole life.

Figure 1. Percentage of Children with Disabilities in the Caribbean

	Antigua	Dominica	St. Kitts & Nevis	St. Vincent & the Grenadines
Of Children’s Population	1.5%	1.2%	1.9%	0.7%
Of National Population	0.4%	0.3%	0.7%	0.3%

Source: UNICEF. State of the World’s Children. Eastern Caribbean Area Supplement. 2013.

Additionally, children affected by Zika may also face stigma and discrimination in the home or from their wider community. ECLAC reported that children with disabilities are generally excluded from normal activities within the home and do not participate in community life. Families often shun or mistreat their disabled children and frequently adequate care is not provided.¹² This information reflects some of UNFPA's findings from a 2018 global report on young persons with disabilities.¹³ UNFPA goes further to say that as children affected by disabilities grow older, they may also face other challenges. Girls with disabilities are less likely than their male peers with disabilities to attend school, making these girls less eligible to hold formal employment and to be literate.¹³ As women, they are more likely to live in poverty and to be subjected to GBV. They are more likely than their male peers are to think of themselves as disabled and to hold a negative self-image. This low self-image in turn can make them more vulnerable to harmful social interactions.¹³ Studies from around the world have found that women and girls with disabilities are at greater risk of sexual violence and exploitation than are either women without disabilities or men with disabilities.¹³

According to stakeholders in the Caribbean, more needs to be done to enable persons with disabilities to maximize their potential to actively participate in society.¹⁴ Too many children with disabilities continue to face barriers to their participation in the civic, social, and cultural affairs of their communities. Across the region, there is a need for on-going public education and awareness programs to address issues of abuse, stigma, discrimination, marginalization, and exclusion of persons with disabilities.¹⁴

ANALYSIS OF THE PROBLEM

Findings from two recent gender analyses carried out in 2019 in Antigua (no activities were conducted in Barbuda) and Dominica in the wake of Zika emergency response efforts highlight key social inclusion themes and reveal that services do exist for persons with disabilities in the Eastern and Southern Caribbean, but they are limited. Compounding this, persons and families of persons with disabilities face barriers that may hinder utilizing those services meant to assist them. Varying perspectives with regards to discrimination and stigma faced by persons with disabilities among community members, health providers, educators, and family members of persons with disabilities possibly contribute to slow improvements in this sector.

Antigua



The discrimination against persons with disabilities and the lack of community understanding has an impact on the families of people with disabilities and special needs. Parents of children with disabilities participating in focus groups in Antigua expressed that there are many financial, emotional, and physical stressors on the family. The impact on families can vary and depends heavily on the extent of a child's disability, the dynamics within the household, the wealth of the household, and the level of community (including employer) support. However, in a focus group discussion with parents of children with severe disabilities, there were significant commonalities and factors that connected them.

Both married and single women with children with disabilities expressed feeling depressed, sad, tired, frustrated, and sleep deprived. They expressed that finances were challenging due to the special care and support (including health, education, therapy, and babysitting) needed for their child. Seeking this

specialized care also takes a lot of time. At least one participant lost her job due to the amount of time she had to take off to care for her child. Parents stated that they sometimes blamed themselves, questioning what they did wrong.

There were additional challenges for families with multiple children, where siblings of persons with disabilities may not be able to enjoy their parents' attention and time as much as they may desire. There are also logistical challenges with transportation and physical challenges lifting children with physical disabilities into chairs, cars, beds, and other support devices. One health provider noted that she sees a lot of guilt in these parents – they feel guilty that they are not able to care for their children the way that they would want to if they had enough time, money, support, and services.

“They will need more time in terms of every aspect of their care. They are tired but out of the love of that child they do what needs to be done.” (Female health provider, Antigua)

“I think who stays home with the child is matter of choice, especially with a child with disabilities, I stayed with my daughter for 4 years at home because there were no specialists available to her, when she was assessed, and she needed therapies, I stayed at home. It’s hard when you don’t have the support and a lot of times you don’t get the family support and community support because the child is a special needs child; you are always looked down upon. We are building awareness about the situation of children, but information/awareness is still needed; a lot has to do with our society and the way we think. Having the awareness of disability helps and helps parents like me to get a job easier and have a better lifestyle not just for us but our children.” (Parent of person with disabilities, Antigua)

“You become stressed out. There were times I would just cry, even though there was 4 of us, my son would have questions...he does not understand. You have to try to do the best with your knowledge, explain and then you still have all the housework to do, you still have to take time out to work with her and take her to the beach to work on legs, take her for her exercises, there is a lot of emotional stress and people don’t understand what you go through. People like to throw words at you and they don’t know what you go through, they are not there when you aren’t sleeping at night, when the child breaks something, and you have to be up physically going through with the strength. The child goes like the Energizer bunny and you have to bring yourself to understand. For whatever reason God has given me this child, I have to lock the doors take a rest, get up and go again and still face the public. Yes, at times we want to tell people certain things because everyone thinks they know how to deal with it...but they don’t know. When I took her to the States it was different, but our culture is not the right way to go about it, parents are stressed out but then you have the public. They need education and we can’t move many mountains. If there is a time to claim, it is now, parents just form themselves into an active support group” (Parent of person with disabilities, Antigua)

Dominica



In Dominica, children with disabilities may face stigma and discrimination in the home or from their wider community. Respondents in discussions mentioned that often times families try to hide people with disabilities away from the community or keep from participating fully in society, like in school or having outside relationships.

“People thought [my cousin] was disabled that she shouldn’t experience certain parts of life like having a boyfriend or pregnancy. The community talks, they think disabled people are not normal so they should stay behind the curtain.” (Woman, Princess Margaret Hospital, Dominica)

“Parents still hide the [disabled] children, sometimes the neighbors say ‘this child has been here all these years,’ and we never know.” (Teacher, Dominica)

Several female focus group participants mentioned that women may feel pressure from society to have healthy children and may take the blame for their children’s failings. Parents, and particularly mothers of children with disabilities or developmental delays, may blame themselves for any perceived negative health results of their child. Focus groups participants also mentioned the need for parents of children with disabilities to seek help and support. They acknowledged that caretakers can face emotional strain and lack the support to cope with the demands of caring for a child with severe disabilities.

“Some women take it differently – they ask ‘what happened, why did this happen, is it a curse? Is it my fault or not? They feel like it’s their fault.” (Woman, Roseau Health Centre, Dominica)

“They don’t know what to do, they feel stigmatized. They should seek counseling to deal with the situation from the church or the health care system.” (Woman, Roseau Health Centre, Dominica)

Additionally, several female focus group participants mentioned the financial burden of caring for children with disabilities. One health provider, who worked with children with disabilities, commented on the financial challenges that caretakers, and particularly mothers, must make. Although there is universal health coverage for children under 16 years of age in Dominica, there are still extra costs for additional specialized tests and assessments, scans, procedures, and medication.

“If she has a disabled child, she won’t be able to work. If she is not able to work, the father may or may not be helping, she might not be able to pay for medical treatment, especially if it requires surgery.” (Health provider, Portsmouth Health Centre, Dominica)

Teachers who worked at a school for children with disabilities in Dominica’s capital had some insight into working with parents of children with disabilities and grappling with public perception and stigma. One teacher recounted how stigma, and a general misunderstanding of what a disability is, can permeate into broader institutions like the education system. Even primary school administrators, according to teachers, have discouraged parents from enrolling their children in the special school, citing that it would make their disabilities worse. Beyond the school system, some families, teachers noted, choose not to enroll their children in the school for disabilities because they face pressure from extended family not to. However, teachers mentioned that parents generally may have little information about their child’s disability and have difficulties coping, disciplining their children, and understanding what medication or health services their children may need. They may also lack the full support of their extended family due to the stigma which exacerbates many caretakers.

Health providers shared that there are limited services for children and people with disabilities available in Dominica. Where they do exist, most are available only in the capital including health specialists like pediatricians and the three private schools for children with disabilities. As a result, families living on other parts of the island are not able to regularly access services or end up paying more for private services or services in other islands. According to teachers, there are some linkages between the health system and schools with disabilities however these also appear to be limited and with much of the burden placed on teachers. A welfare system also provides some financial assistance but generally parents don't have much support.

"Some parents said that the principal of the primary school told them not to bring the child here [school for disabled], that it would make them more retarded. There is a lot of misunderstanding and stigma." (Teacher, Dominica)

"We have a list from the Ministry [of Education] of children with disabilities, but some parents don't show up with their kids. They get pressure from family members to not bring them in ..." (Teacher, Dominica)

"The parents can't even explain to you what their disability is, we are the ones that are discovering and giving them recommendations." (Teacher, Dominica)

"We have a mother here, she had so much difficulty giving her [disabled] son his medication, so we help out. She was so relieved that we were helping, she didn't have family support." (Teacher, Dominica)

"There isn't a pediatrician here [Portsmouth] in the public system. There is a private one down the road or you would make an appointment at the Princess Margaret Hospital – they have to find transportation." (Health provider, Portsmouth Health Centre, Dominica)

"There is a referral mechanism in place to deal with cases [of birth defects] that cannot be dealt with in Dominica, we refer them to Martinique for management. ... There is a lack of specialists here. We can do head ultrasounds, X-rays ...CT scans of the heads, but that's it. We don't have neurologists or neurosurgeons, no ophthalmologists for neonates, which is particularly a challenge for premature babies." (Health provider, Princess Margaret Hospital, Dominica)

"Under the health care, the nurses come in and give a physical, mental, vision, and hearing check – sometimes they discover new things, one kid didn't know he had a heart problem. We teachers take notes and then follow-up with parents 'have you gotten the test?'" (Teacher, Dominica)

"Social services like welfare are available to assist parents when they have disabled infants, but there are no professional institutions." (Health provider, Princess Margaret Hospital, Dominica)

IMPACT OF PROGRAMS LIKE CARE PROJECT – ANTIGUA

There is a perception that stigma and discrimination towards persons with disabilities in Antigua and Dominica occur and bring additional challenges that can impact health care and educational access and utilization. While specialized services for persons with disabilities exist, they are limited. More needs to be done to improve these services and to increase access and awareness. In Antigua, one such program – Care Project – is working to bridge this gap, providing care and support services for children and

families affected by disabilities as well as advocating for more public education and raising the conversation on issues affecting the differently-abled community.

Care Project in Antigua is a government facility, which provides a home and basic care for children with severe mental and physical disabilities. It is the only government-funded program of its kind for persons with disabilities. While some children are brought in for day services, many of Care Project's residents have been abandoned by their families and are wards of the State. Although it primarily services children, the age of the residents ranges from 8-48. Those under care of Care Project suffer from a spectrum of illnesses and conditions including Cerebral Palsy, Autism, Hydrocephalus, blindness, seizures and many neurological diseases.



Artwork done by children at Care Project.
PHOTO: MORGAN MICKLE FOR THE USAID ASSIST PROJECT

According to both parents of children with disabilities and health providers in Antigua, sometimes when a child is born with a disability, it is viewed as “her (the mother’s) child” and the man flees, and other times, men get more involved in the child’s life. The latter was evidenced by the involved fathers at Care Project; almost half of participants in a focus group with parents (12 parents in total) were fathers of children with disabilities and expressed being very involved in loving, raising, and caring for their child. One father noted that raising a child with special needs must fall on the shoulders of both parents. However, two mothers of children with disabilities stated that as soon as they found out the child had special needs, their partner left, not wanting to deal with the additional challenges they would have to face in raising that child. Several women expressed feeling blamed.

“It could go either way. The man could flee or he could get more involved to help.” (Female health provider, Antigua)

“She is heavy, you don’t sleep, you have to get the other children ready and then you are tired. When you are out people will just stare, comment, and make you feel uncomfortable. I keep her at home; there are times when I’m home alone and I just drop to the floor and start crying. My partner abandoned me when she was born; I had to pay for care but with Care Project it’s easier; I had to take the child to work but my boss said I couldn’t bring her; they thought I was complaining. I was laughed at, shunned.” (Parent of person with disabilities, Antigua)

Being a parent involved with Care Project has led to many realizations around disability and services, and overall positive impacts for families. Parents of children with disabilities expressed that there is a lack of awareness of services available to them and their children at the primary health center and more broadly in Antigua. Many did not know Care Project existed until their child was a few years old due to lack of messaging from providers

“We need more group support, like AA meetings, but for kids like that or for mothers.” (Parent of person with disabilities, Antigua)

and in the community. They expressed a sincere gratitude for Care Project but wished that they had known about it sooner considering that regular day care would not accept their children.

“For me, I never knew there were persons in Antigua [with disabilities]. Those things you see on television, not here. Public awareness should be at the forefront. The awareness is not what it should be.” (Parent of person with disabilities, Antigua)

“Now people know more about Care Project. We are on the radio and people know my face. We use public awareness to curb stigma people face in the communities. Up until 2015, 90% of people didn’t know about care project until I mentioned it.” (Matron of Care Project, Antigua)

These parents, the staff of Care Project, and other health providers felt that Care Project needed to be expanded to accommodate more people. Further, parents of children with disabilities expressed a desire for even more awareness about the specialists (e.g., speech therapists and physical therapists) on the island, their hours, and the associated costs. Finally, parents felt that there are not enough psychosocial support services available to them and expressed a desire for a support group for families of persons with disabilities. Participation in the focus group sparked interest and facilitated an exchange of contact information at the end in hopes of starting one in the future. Programs like Care Project model a community that can provide many benefits to persons and families affected by disabilities including care assistance, decreased financial burden, increased psycho-emotional support, improved knowledge related to disability care, opportunities for advocacy, and solidarity. As such, programs like these across the Caribbean can be developed or strengthened, and ultimately work towards improving equitable and inclusive health services and well-being of populations in the region.

LOOKING FORWARD

Although Zika is no longer a significant threat to the Caribbean region, learning from the Zika outbreak can be applied to strengthen the health system more broadly. The social inclusion of persons with disabilities, including children and families affected by Zika, needs to be further prioritized and addressed. The Governments of Antigua and Barbuda and Dominica, including the Ministries of Health, as well as other Caribbean governments have opportunities to improve services and support systems for families and to strengthen provider capabilities to respond to these needs. In doing so, policy makers and implementers must also be aware of generalizations about “disability” or “people with disabilities” that can be misleading. Like their peers without disabilities, persons with disabilities have diverse gender, age, socioeconomic, sexuality, ethnic, and cultural identities. Disabilities themselves and the associated needs also vary widely. These diversities must be taken into consideration in order to improve equitable quality health care.

Findings from Antigua and Dominica revealed that there is limited public understanding, information, and awareness around disabilities and as such, these areas should be targeted for improvement. Families of persons with disabilities, teachers, and health providers expressed that such improvements are needed particularly to help reduce stigma and discrimination and draw attention to service availability (health services, education opportunities, and financial support) and constraints. Public education, information sharing, and awareness raising could be done through jingles, advertisements on television or the radio, posters in health centers and hospitals, community-based campaigns, and through programming at

schools. Programs like Care Project can play a large role in helping to advocate for some of these changes and lead/co-lead efforts with other partners embedded in the health system. Additionally, to increase knowledge of resources, parents involved with Care Project suggested spreading the word about the facility and its services through community-based opportunities like marches and events.

Findings also revealed that there is a desire for more counselling opportunities and community support mechanisms for families. Peer-to-peer groups such as one in the making at Care Project could be one such avenue, but counselling should also be provided at the hospital, health centers, and in schools (with professionals trained in psychosocial support and counselling approaches) and linked with mental health programs where possible. Under the USAID ASSIST Project for instance, health care providers in Antigua and Dominica were recently trained in providing psychosocial support; these efforts can be strengthened and institutionalized. ASSIST is supporting this initiative through a series of activities such as developing a psychosocial support provider-patient checklist for health care providers to use during counseling sessions, creating a screening or self-assessment tool to help caregivers identify when further specialized referral is needed, and co-developing guidelines for psychosocial support with the Ministries of Health. To continually improve the knowledge of trained professionals and the level/quality of care they provide to clients, one health provider in Antigua recommended establishing a ‘network of psychosocial care providers’ (possibly over Facebook or WhatsApp) across the Caribbean islands. As there is a limited number of professionals in this space, fostering communication across the Caribbean islands would allow for knowledge exchange of best practices, new research, and solutions to common challenges. Finally, an emphasis on scholarships for students to study counselling, social work, speech therapy, physical therapy, etc. (key areas that currently face staffing limitations) could help increase the number of qualified professionals for these critical services.

To increase accessibility of services, locating specialists together in one complex and offering night and weekend hours may help families who may face additional challenges securing transportation and using resources to reach many separate locations. One provider in Antigua described the ideal situation as one that would create a “referral unit” that could provide all the services such as education, counselling for well-visits, counselling for sick-visits, social work, financial assistance, and nursing. Currently referral services are spread out and sometimes difficult to reach. This referral unit could be centralized to start then adapted over time to meet the needs of different geographical areas.

Finally, improved intra-country coordination among ministries, such as harmonizing efforts between the Ministry of Health and the Ministry of Education, and with strengthened linkages to programs like Care Project that work specifically with families of persons with disabilities could be beneficial to share best practices and approaches that could result in more supportive environments for persons with disabilities, their families, and overall healthier populations.

For more information:

USAID Applying Science to Strengthen and Improve Systems (ASSIST) Project
University Research Co., LLC • 5404 Wisconsin Avenue, Suite 800 • Chevy Chase, MD 20815-3594,
USA

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